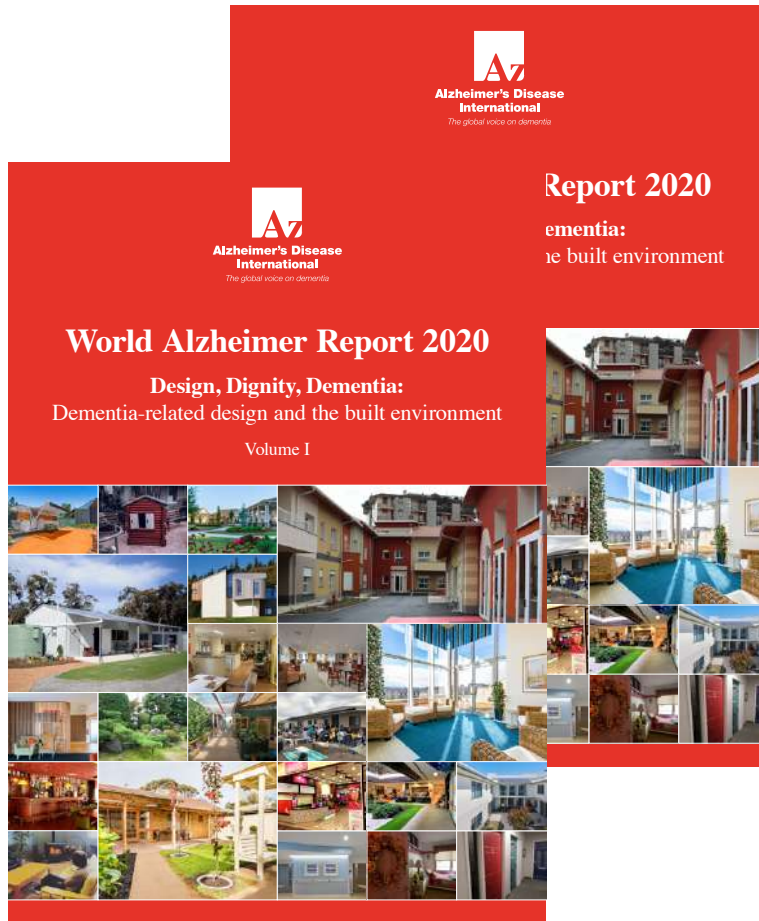


ADI Virtual Side Event and Report Launch



World Alzheimer Report 2020

Design, dignity and dementia;
dementia-related design and the
built environment

Welcome & Introductions

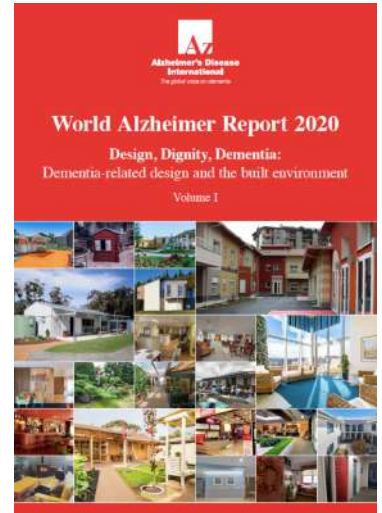


Paola Barbarino

CEO,

Alzheimer's Disease International (ADI)

@AlzDisInt



Engage on social media



Follow ADI on Twitter, Instagram & LinkedIn @AlzDisInt
Facebook /alzheimersdiseaseinternational

Use the hashtags #WorldAlzReport #WorldAlzMonth
#LetsTalkAboutDementia



Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

10-12 December 2020
VIRTUAL CONFERENCE



**VIRTUAL
2020**

ALZHEIMER'S DISEASE INTERNATIONAL
VIRTUAL INTERNATIONAL
CONFERENCE



**During this COVID-19 emergency period
please make a donation, however large or small,
to ensure we can continue to make a real difference.**

**ADI will continue to help people living with dementia
and their carers to live a better life during this emergency.**

DONATE NOW

<https://www.alz.co.uk/donate>

Poll

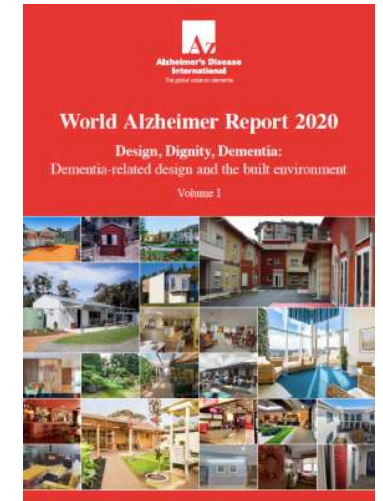


We are interested in learning more about you



Speakers

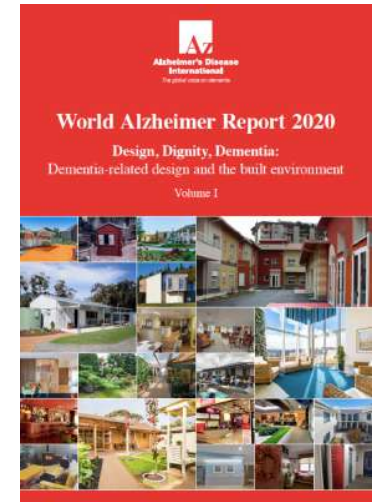
- **Professor Richard Fleming, report lead**
- **Dr. John Zeisel, report co-lead**
- **Kirsty Bennett, report co-lead**
- **Kate Swaffer – CEO, Dementia Alliance International**
- **Kevin Charras, Ph.D - Centre Hospitalier Universitaire de Rennes**
- **Wilhelmina Hoffman, M.D., Silviahemmet**
- **Dr. Ishtar Govia, STRiDE Jamaica**
- **Dr. Alison Dawson, University of Stirling**



Professor Richard Fleming

Professorial Fellow, Faculty of
Science Medicine and Health,
University of Wollongong

Executive Director, Dementia
Training Australia



Principles, context and recommendations

Professor Richard Fleming

Academic Lead – World Alzheimer's Report 2020

Principles



In comparison with many other fields, designing for people living with dementia does not have a large knowledge base.

Nevertheless, there is a sufficient range of views and isolated 'facts' that writing a report on the field would be made much easier if the contributors could, by and large, agree to use a small set of principles of design to structure their thoughts and writing.

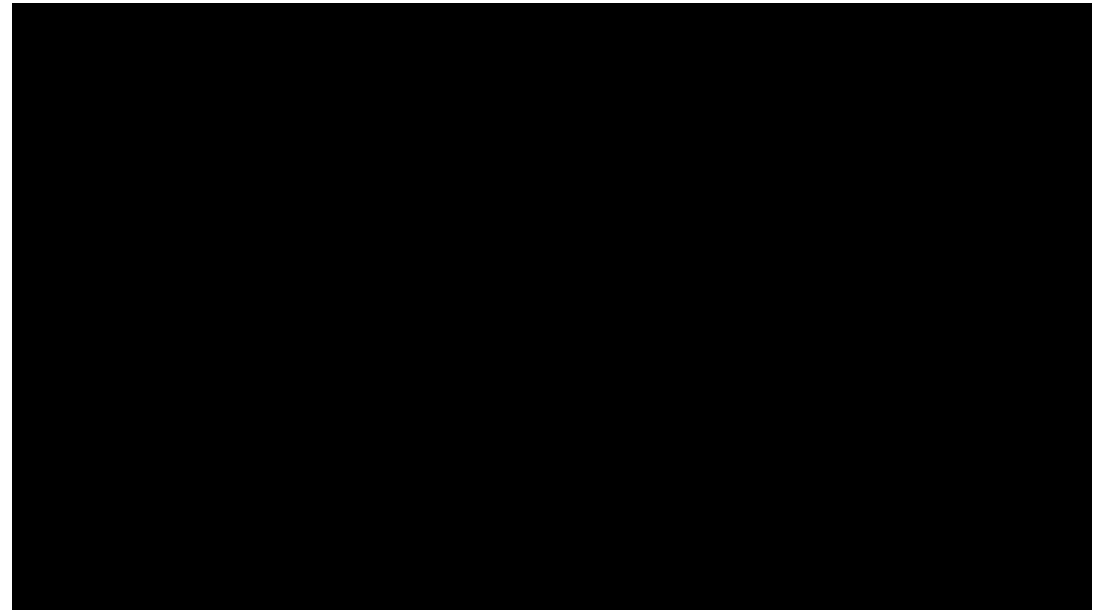


Principles



In comparison with many other fields, designing for people living with dementia does not have a large knowledge base.

Nevertheless, there is a sufficient range of views and isolated 'facts' that writing a report on the field would be made much easier if the contributors could, by and large, agree to use a small set of principles of design to structure their thoughts and writing.



Global context



The extent to which designing specifically for people living with dementia is taking place around the world has not, to this point, been explored. The writing of this report provided an opportunity to begin this exploration and resulted in 84 case studies from 27 countries being identified.



Recommendations

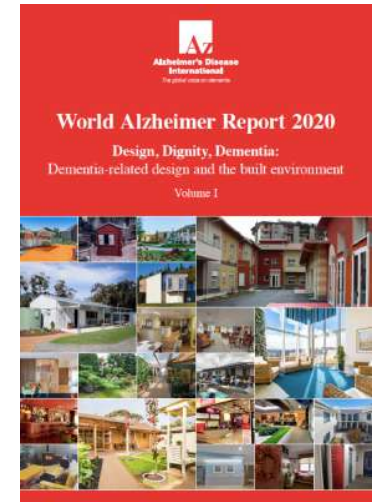


There has been progress, but much remains to be done and it needs to be done with careful consideration of context and the over-arching goal of affording dignity to people living with dementia.

1. Common set of design principles
2. Inclusion in National Dementia Plans
3. Work with advocacy groups to promote dementia as a disability and the adoption of dementia design guidelines
4. Include designing for people living with dementia in the curricula of schools of architecture and design
5. Encourage health economists to collaborate with designers on investigating the costs and benefits of supporting people with dementia to live in their communities.
6. Encourage the translation of knowledge
7. Encourage National Dementia Associations to promote the use of the available knowledge
8. Encourage governments to be proactive in engaging architects, operators and other key stakeholders in designing for people living with dementia

Dr. John Zeisel

President & Co-Founder of
Hearthstone Alzheimer Care, Ltd.



Groundbreakers Past, Present, & Interviews

Dr. John Zeisel

Co-lead World Alzheimer's Report 2020

Little did we know then



- *In the 1970's & 1980's*
- *Professionals in social & psychological sciences and in design*
- *Had no idea that dementia would grow into the world-wide challenge it presents today*
- Mini Mental State Exam (MMSE) – Folstein
- Global Deterioration Scale (GDS) – Reisberg
- Environmental Psychology – Proshansky
- EDRA – Environmental Design Research Association
- Design for Dementia becomes a field of study

Groundbreaking Projects 1978-1998

Year	Groundbreaking Paradigm Shifters	Principles & approaches the designers / operators explored in this environment
1978	Le Cantou, Rueil-Malmaison, France	Separate small apartment in larger building, continued family involvement
1984	Aldersgate, Felixstowe, SA, Australia	Process innovation; non-institutional quality; redundant cuing
1987	Pepper Tree Lodge, Queanbeyan, AU	Unit for the Confused and Disturbed Elderly (CADE) broke Australia's institutional model
1989	Anton Pieckhofje, Haarlem, NL	'Family scale', central services, differentiated style management
1991	Adards, Warrane, Tasmania	Homelike, accordion design to switch between "family" & "community" scale", lively garden
1991	Woodside Place, Pennsylvania USA	Neighborhoods with joint common space, family scale gardens, innovative details
1995	Hearthstone, Massachusetts USA	"Community scale," central garden, engagement activities at "family" scale
1996	Himawari, Ofenatu Japan	First "family scale" in Japan
1997	Moorside, Winchester UK	Choice through design, unobtrusive care, Seeing and being seen
1998	Hasselknuten, Sweden	In town location, common areas open to the public, normalized life

Approaches discovered

today common sense / then groundbreaking



- Location in the community
- Family scale neighborhoods,
- Homelike & non-institutional
- Community scale commons
- Public invited into the Bistro
- Gardens full of life
- Engagement all day long
- Redundant cueing
- Resident choice by design
- Naturally mapped
- Seeing and being seen
- Community scale
- Stable staff
- Care that fits into life

Living groundbreaker interviews

- **Pioneers**

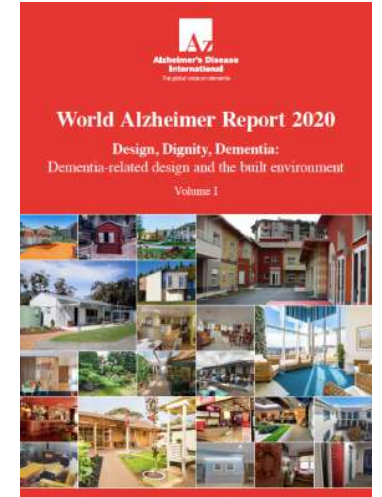
- Margaret Calkins – *Architect, Pioneer Researcher*
- Clare Cooper-Marcus – *Pioneer Garden Guru*

- **Innovative architects**

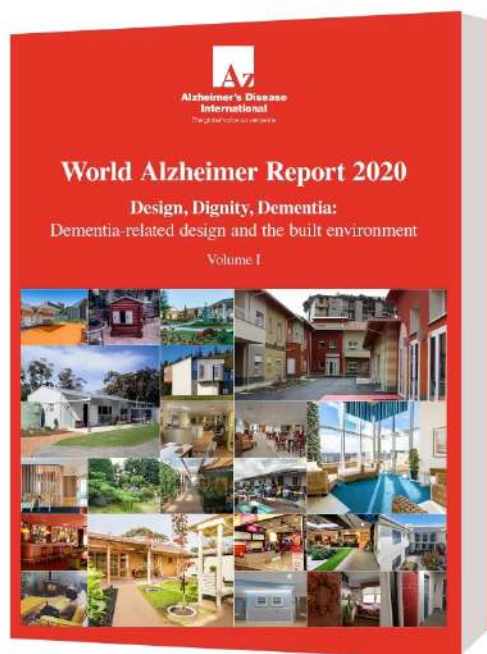
- Allen Kong – *Multi-Cultural Architect*
- Peter Phippen – *Groundbreaking architect & Innovator*
- Michael Murphy – *International Design Thinker*

- **Paradigm Shifters**

- Jannette Spiering – *Serial Innovator*
- Wilhelmina Hoffman – *Geriatrician-Designer-Innovator*
- Alan Dilani – *Salutogenic Champion*



The Interviews



World Alzheimer Report 2020

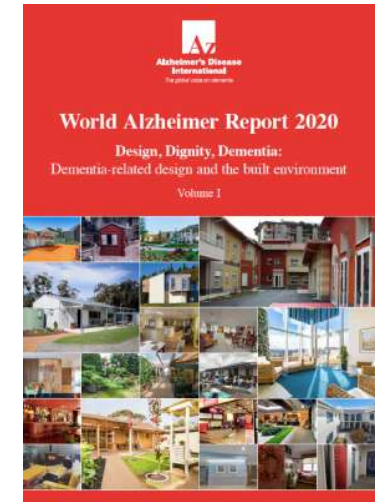
Design, Dignity, Dementia:
Dementia-related design and the built environment

<https://www.alz.co.uk/research/world-report-2020>

Kirsty Bennett

Senior Academic Consultant,
Environments, Dementia Training
Australia, University of
Wollongong

FRAIA Architect Australia



Cultural aspects of designing for people living with dementia

Kirsty Bennett Architect FRAIA
Co-lead World Alzheimer Report

Cultural aspects of designing for people living with dementia



- Four domains (overarching goals, principles, approaches, responses)
- Principles the key in responding to culture
- Importance of context
- Focus on briefing
- Allow time

Cultural aspects of designing for people living with dementia



Cultural aspects of designing for people living with dementia



Education and training

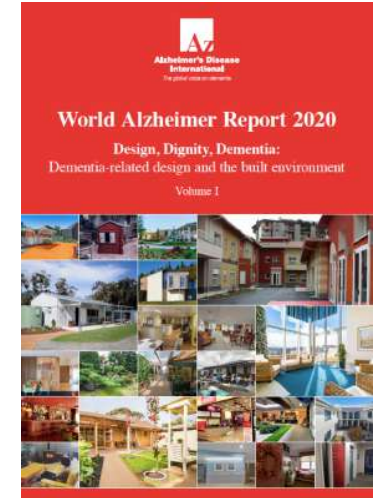


- Report show cases well developed approaches
- In aged care organizations, universities, and companies
- Australia, Japan, Singapore, Canada, USA, UK
- Essential part of knowledge translation
- Include education in the curricula of schools of architecture and design.

Kate Swaffer

Chair, CEO and Co-Founder,
Dementia Alliance International
(DAI)

Board Member, ADI



Disability Rights, Enabling Design and Dementia

Kate Swaffer

MSc, BPsych, BA, Retired nurse

Chair, CEO & Co-founder, DAI

Board member, ADI

@KateSwaffer
@DementiaAlliance



Reframing Dementia as a disAbility



Dementia is a major cause of disability and dependency among older people worldwide.

World Health Organisation, 2019, Dementia Factsheets, <https://www.who.int/news-room/fact-sheets/detail/dementia>

@KateSwaffer
@DementiaAllianc

Support and Advocacy, of, by and for people with dementia



Human and Legal Rights

- Even though people with dementia still retain the same rights as anyone else in society, including human rights and disability rights, **there has been little change in the realisation of these rights;**
- **No longer can we pick and choose what rights we wish to uphold,** or only focus on e.g. rights to dignity or health, which when interpreted do not disrupt the current medicalised approach to dementia;
- **Disability Rights Matter** to everyone.

@KateSwaffer
@DementiaAlliance

Support and Advocacy, of, by and for people with dementia





The built environment and disability

- The environment's influence in creating disability or in increasing it has been well established;
- It is seen as integral to the definition of disability;
- When the built environment changes, then the experience of someone living with a disability will also change.

@KateSwaffer
@DementiaAllianc

Thank you



We must all work towards ensuring the built environment for people with dementia is accessible.

We don't need more reports or more rhetoric.

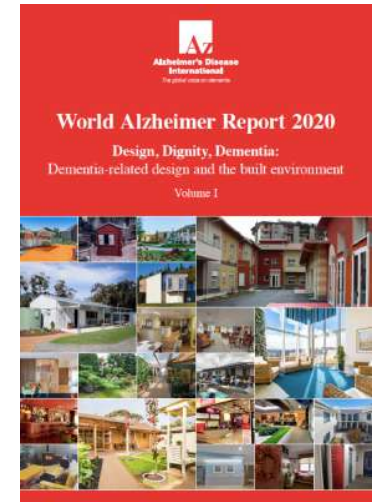
We need ACTION! Now!

Support and Advocacy, of, by and for people with dementia



Kevin Charras, PhD

Living Lab Vieillissement &
Vulnérabilités, Service de
Gériatrie, Centre Hospitalier
Universitaire de Rennes, France



Human Rights, design and dementia:

*Moving towards an **inclusive approach***

Kevin Charras, Ph.D

Living lab Vieillissement et Vulnérabilité

CHU de Rennes

Human right based approach of design

Fighting
injustice



Promoting
competencies

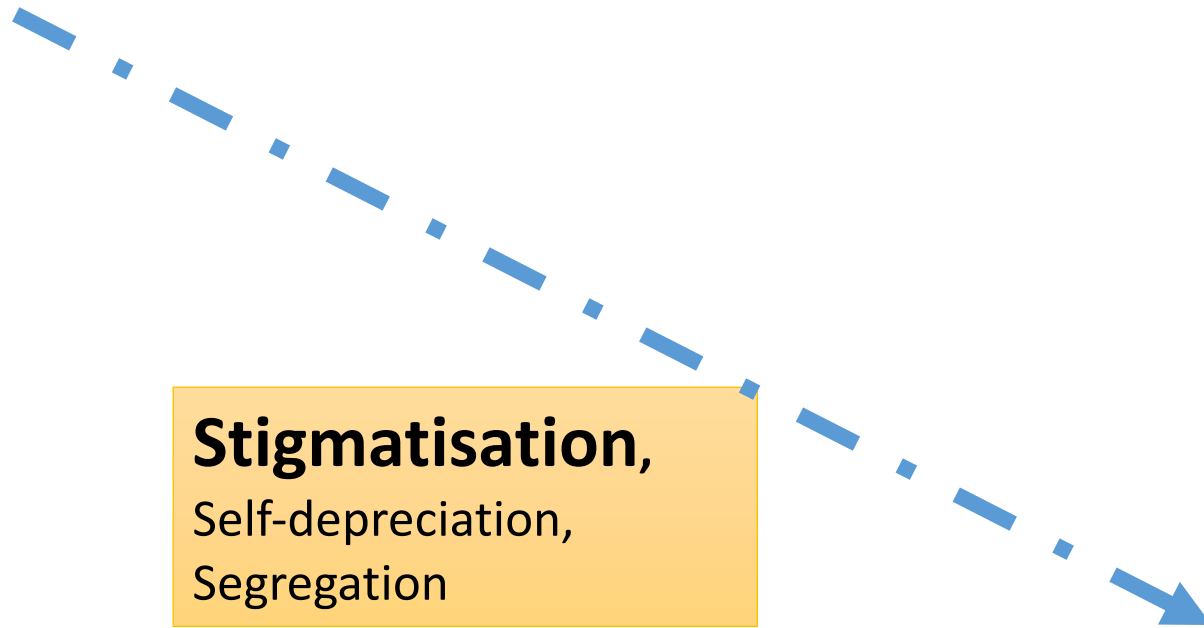


Spaces and **settings** are cues of social and **societal** representations and **attitudes**

Common belief
that people with
dementia should be
contained in **specific**
environments and
continuously under
surveillance

Stigmatisation,
Self-depreciation,
Segregation

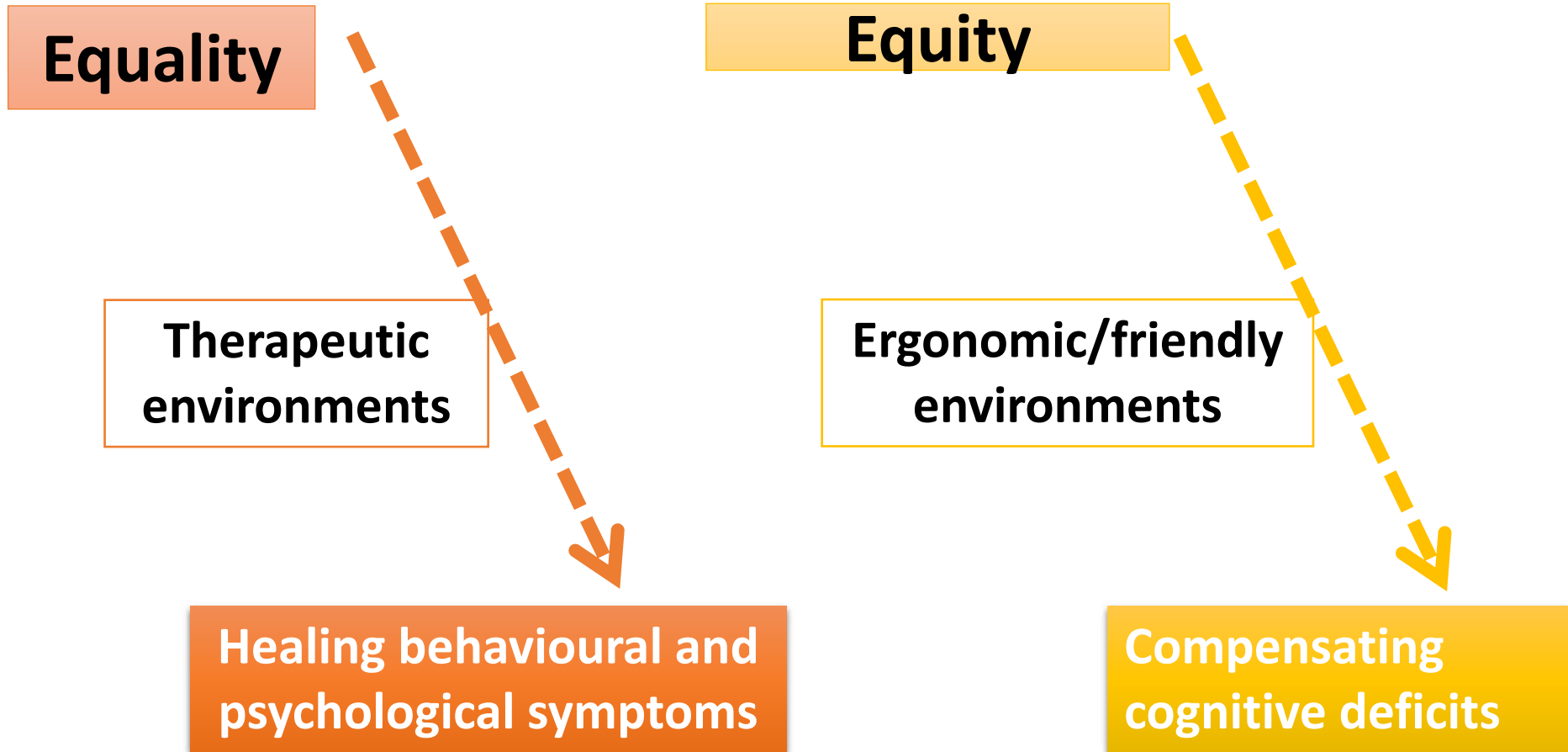
Triggering **maladapted**
behavioural schemes
linked to deficiencies → Self-
fulfilling prophecies



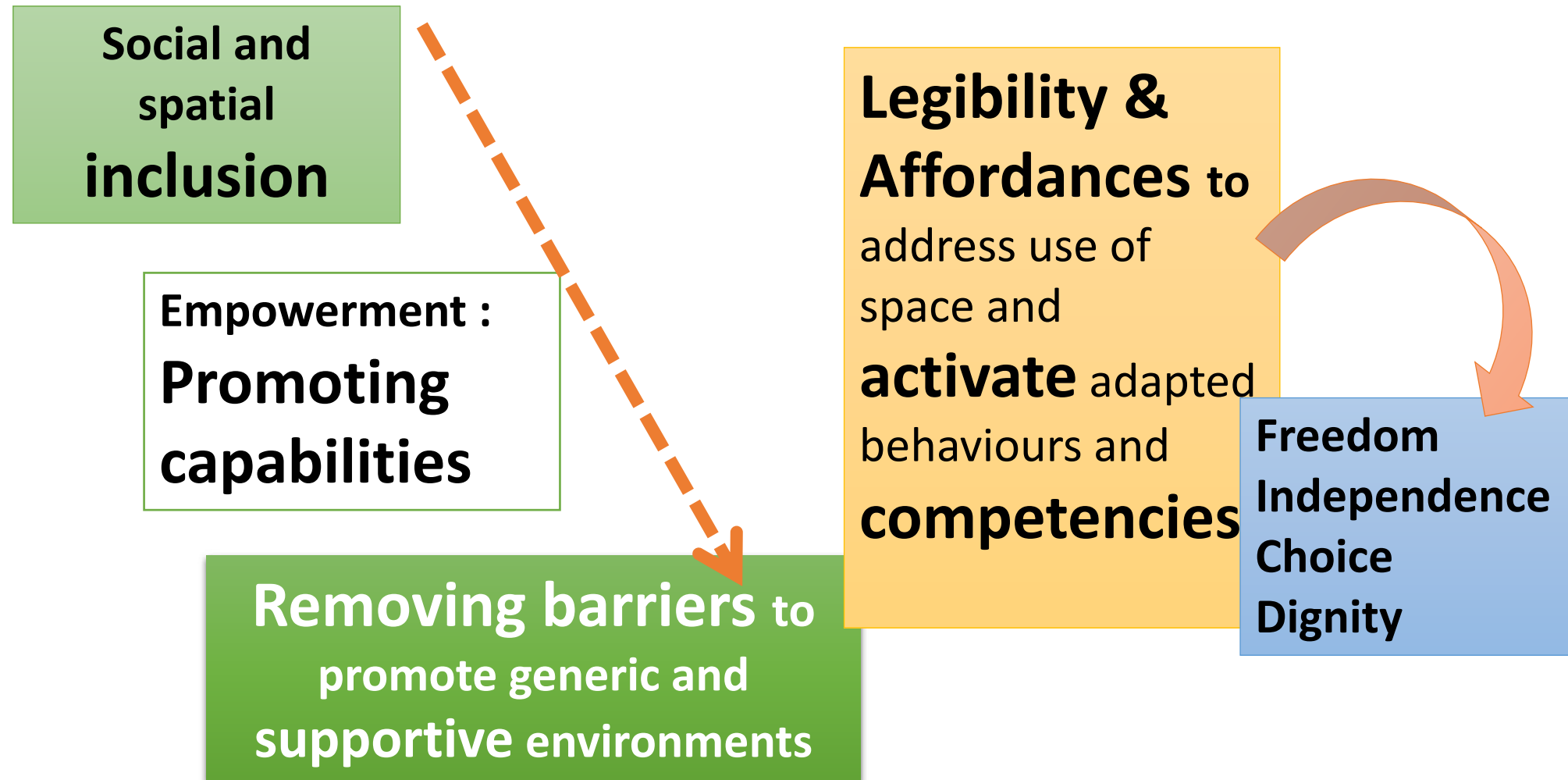
Dementia design induced stigmas



Advances in research on design and dementia



Inclusive design is a challenge for architects, designers and dementia care stakeholders



People with dementia also have **the right to age in place**

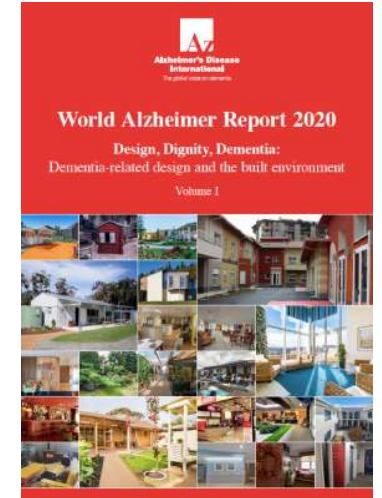
- **Maintaining independence** and autonomy
 - **Connecting to** social support, networks, and **community**
 - **Encountering** cultural, generational and human **diversity**
- Addressing **social health** issues :
 - (1) capacity to **fulfil** potential and **obligations**;
 - (2) ability to **manage life** with some degree of independence;
 - (3) **participation** in social activities.

Inclusive design should prompt and be prompted by social and societal inclusiveness

Wilhelmina Hoffman, M.D.

Principal and CEO, Stiftelsen
Silviahemmet

President, national competence
centre for dementia in Sweden
'The Swedish Dementia Centre'

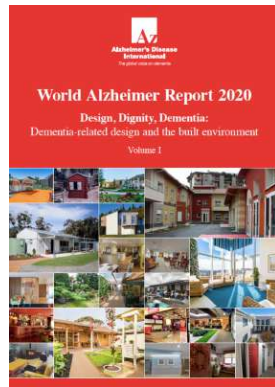


The foundation Stiftelsen Silviahemmet

Dementia - Education and Care for Quality Of Life since 1996



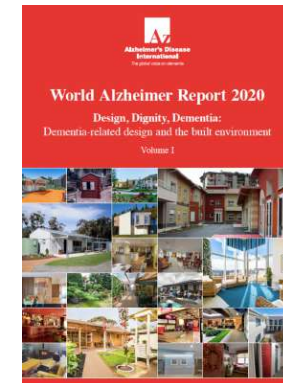
Photo: Yanan Li



The idea of SilviaBo
started with a cup of tea



www.silviahemmet.se



SilviaBo



Photo: Yanan Li



A cooperation between knowhow about dementia
- *Silviahemmet*, housebuilding - *BoKlok* and IKEA

www.silviahemmet.se

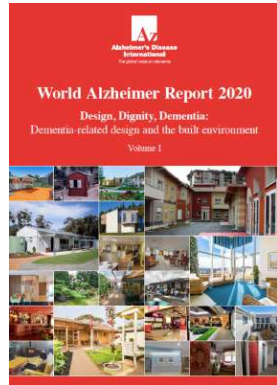
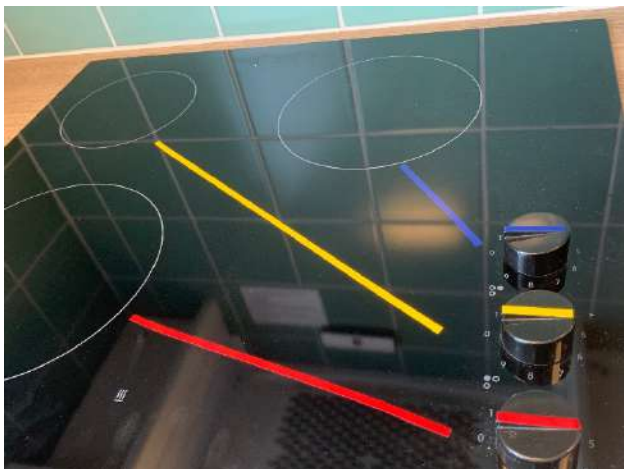
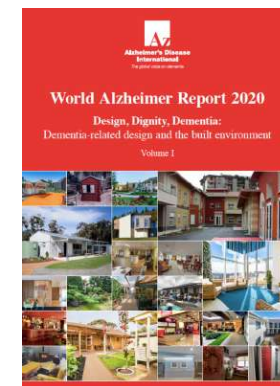




Photo: Yanan Li



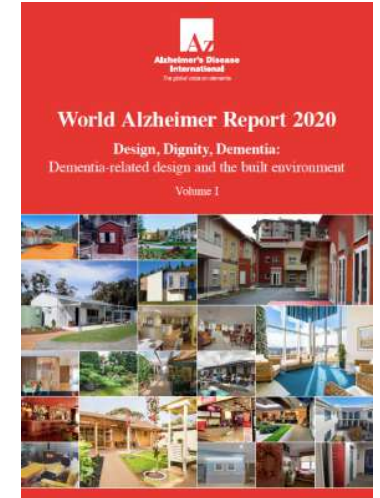
www.silviahemmet.se



Dr. Ishtar Govia

Strengthening Responses to
Dementia in Developing Countries
(STRiDE) Jamaica Project Lead

Lecturer, Caribbean Institute for
Health Research (CAIHR) –
Epidemiology Research Unit, The
University of the West Indies,
Mona Campus



Strengthening Responses to Dementia in Developing Countries

DEMENTIA, DESIGN AND DEVELOPMENT: APPROACHES AND RECOMMENDATIONS FROM STRiDE COUNTRIES

Presenter: Ishtar Govia, Ph.D., M.T.S, M.A.

STRiDE Jamaica Project Lead & Chapter Lead

Alzheimer's Disease International: World Alzheimer's Report Launch 2020

Monday 21 September 2020, 13:00 p.m. - 14:15 pm (BST)



stride.dementia@lse.ac.uk



Diversity & Choice



Challenges in LMICs in Designing for Dementia

Most care homes privately-operated and costly

The average older person in a LMIC does not belong to a high-income group

Lack of awareness and systems to safeguard persons with dementia

Existing environmental challenges

Dementia not seen as a national priority

Presence of stigma (further exacerbated by COVID-19)

Key Findings & Recommendations for Designing for Dementia in LMICs

Safety is a top priority in all contexts and is a family responsibility in LMICS

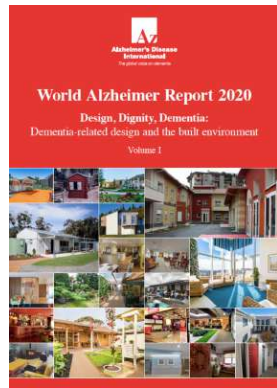


Cultural adaptation to application of principles is a must



Care home site: India

Design principles are not feasible in some contexts



Key Findings & Recommendations for Designing for Dementia in LMICs

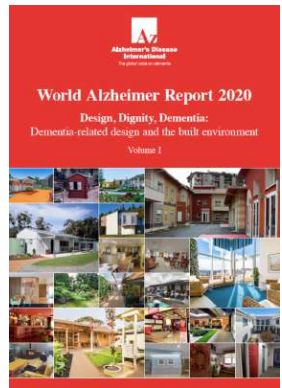
Creative solutions occur in low-resourced settings



Dementia is an issue in LTC and should be incorporated in other policies in LMICs



Assumptions of the principles need to be adjusted in low-resourced contexts



From the co-authors: Thank you!

@ishtargovia

email: stridejamaica@gmail.com



Ishtar Govia

Caribbean Institute for Health
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Rochelle Amour

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Alzheimer's Indonesia, Jakarta,
Indonesia

@ardsi



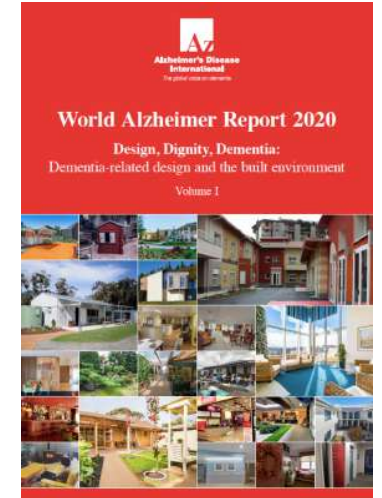
Narendhar Ramsamy

Alzheimer's and Related
Disorders Society of India
(ARDSI), Raghu Nagar, New
Delhi, India

Dr. Alison Dawson

Senior Research Fellow, Faculty
of Social Sciences, University of
Stirling

Co-Leader of the Faculty's
Dementia and Ageing Research
Group



Lessons from COVID-19 and impacts on dementia design



Special thanks to:

Chris Lynch and colleagues at Alzheimer's Disease International

Richard Fleming, John Zeisel and Kirsty Bennett, ADI World Report 2020 leads

Whitney Berta and Frances Morton-Chang, Institute of Health Policy, Management & Evaluation, Dalla Lana School of Public Health, University of Toronto

Lesley Palmer and Martin Quirke, Dementia Services Development Centre, University of Stirling

Alison Dawson, Faculty of Social Sciences, University of Stirling

Email: a.s.f.dawson@stir.ac.uk

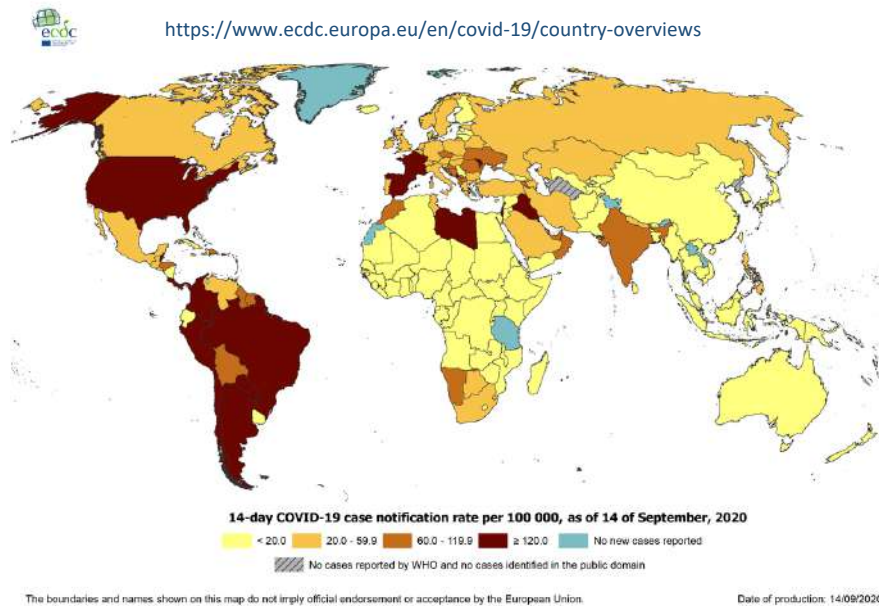
The Dementia Services Development Centre (DSDC): <https://dementia.stir.ac.uk/>

BE THE DIFFERENCE

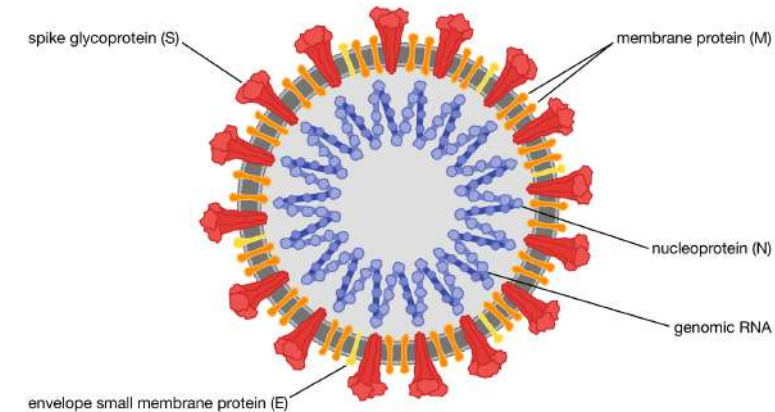
Lessons from COVID-19



- We are all vulnerable



Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)



© Encyclopædia Britannica, Inc. <https://www.britannica.com/science/coronavirus-virus-group>

- We are learning but we still know very little

Lessons from COVID-19

- Social and physical interaction are important



- Front-line workers are critical



Impact on dementia design



- Privilege design to meet clinical / medical needs
- Question whether dementia design can be 'fit for purpose'
- Encourage invention and innovation

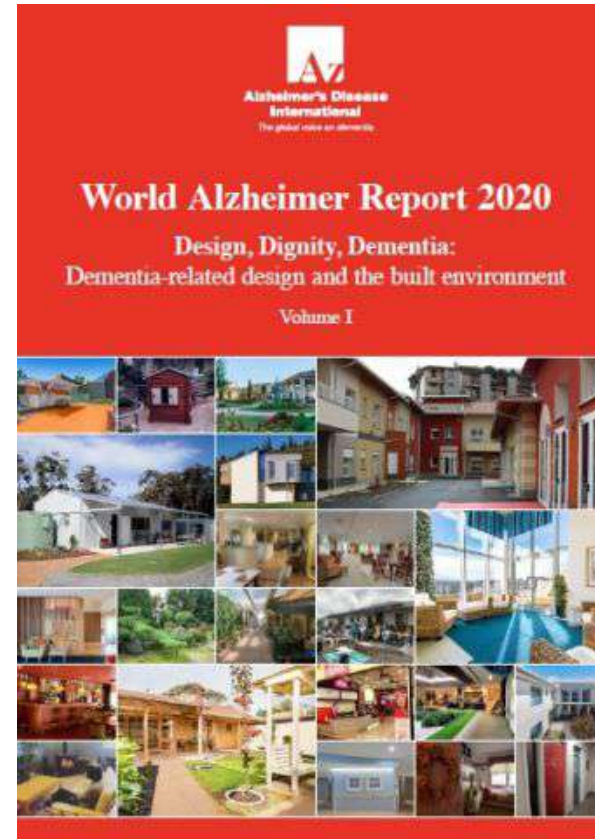


COVID-19 and design: a call to action



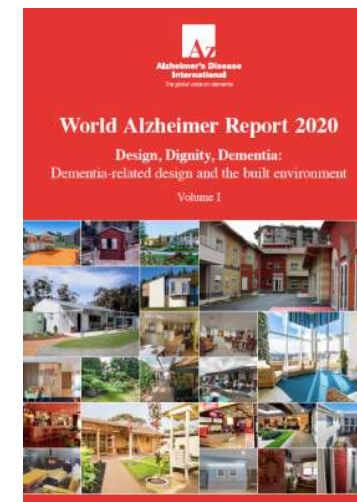
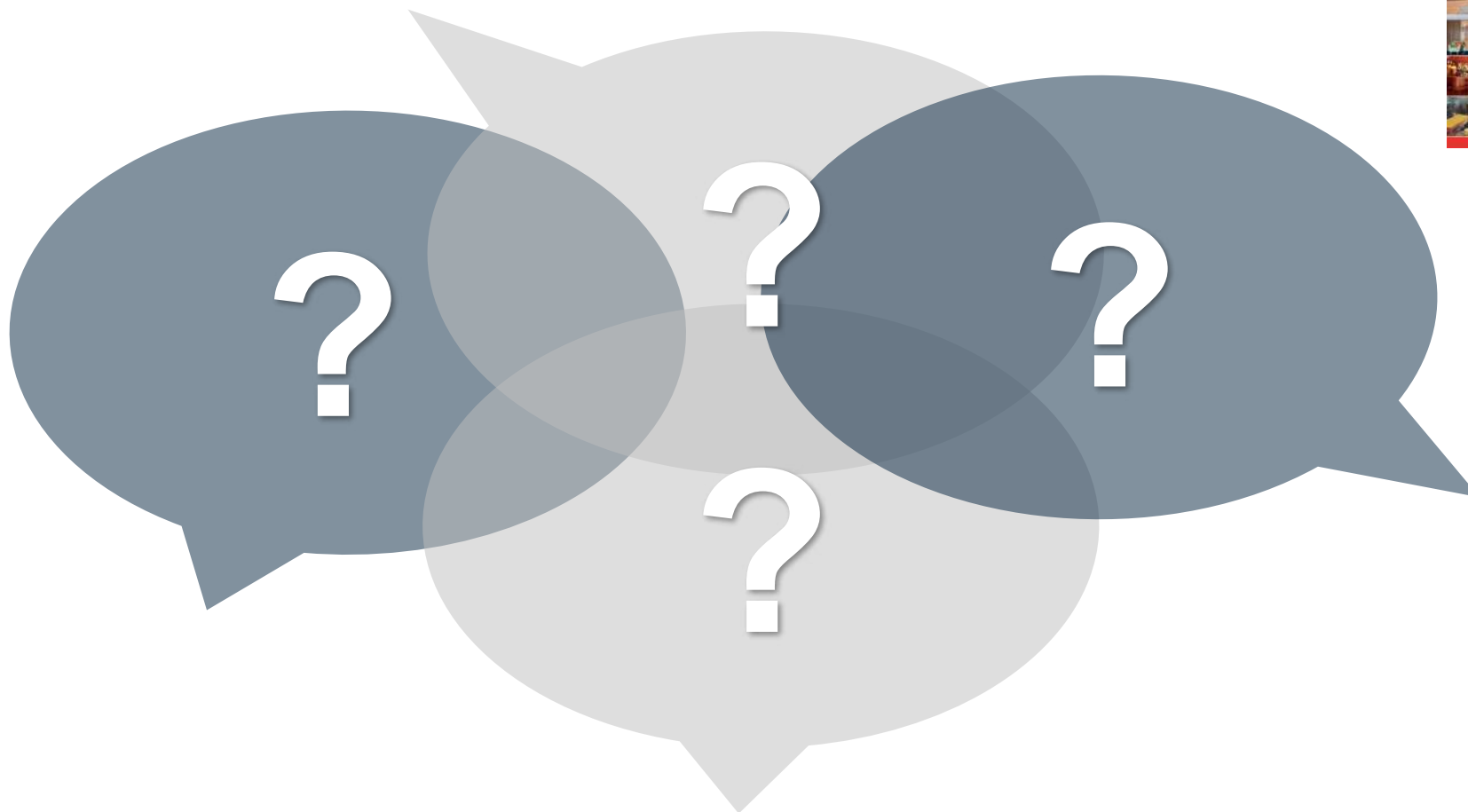
We must reach across
academia, practice and
lived experience and:

- Revisit dementia design principles
- Recognise rights and manage risks
- (Re-)design for context



<https://www.alz.co.uk/research/world-report-2020>

Question and answer



@AlzDisInt

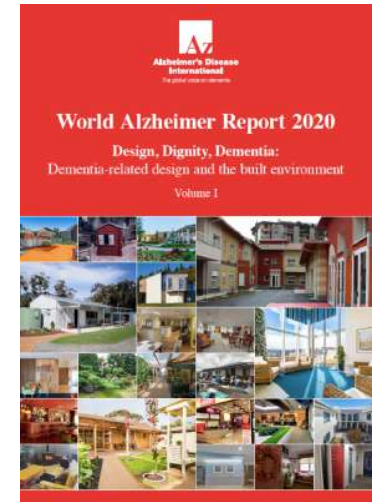
Closing remarks



Paola Barbarino

CEO,

Alzheimer's Disease International (ADI)



Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

10-12 December 2020
VIRTUAL CONFERENCE



**VIRTUAL
2020**

ALZHEIMER'S DISEASE INTERNATIONAL
VIRTUAL INTERNATIONAL
CONFERENCE





**Alzheimer's Disease
International**

The global voice on dementia

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